

Caregiver Support Line Presentation - Transcript

Series: Care for the Caregiver

Topic: Creating a Space for You: Caring for a Loved One at Home

Hello. I am so pleased that you were able to set aside this time to listen to this presentation. We all know how difficult it can be to take the time to focus on you and your own needs, so we hope this presentation will be a worthy use of your valuable time.

The topic for this presentation is, "Creating a Space for You: Caring for a Loved One at Home." I want to start by giving you a bit of an overview that describes how we will focus our time.

The presentation will focus on exploring the unique challenges of caring for a Veteran whose illness or injury can make it challenging to leave the home, whether for medical appointments, trips, or even a short drive into town.

Caregiving for a loved one is truly a gift of your energy and attention, and while it can provide you great satisfaction, it can also stress and strain the Caregiver. Caring for someone for whom leaving the home may be difficult, can significantly impact the Caregiver's ability to come and go freely and naturally this may color the experience of caregiving.

I hope to look at how caregiving may impact you, the challenges you face, and begin to explore ideas that may help you create the sacred space you need to take care of yourself.

I will actually start today by taking apart the word homebound and will explore the potential meanings one might attribute to the words home and bound.

Each one of us has our own personal feelings, images, thoughts, memories, and beliefs that come to mind when we think of home. What does home mean to you? Is home a place of comfort? Is home where your heart is? Is it a place of conflict or uncertainty? Is home a source of pride? Does it reflect who you are or what matters to you? Your current experience of home will either positively support your caregiving experience or potentially make it more difficult.



Even if your home is a place of great comfort, security, order, and beauty, being bound to it can feel restrictive unless you are able to work within these confines to create a space for you.

There are so many aspects to explore when we are talking about what home may provide for us. In the best of all worlds, a home is created to provide you safety and protection. Home provides comfort and nurturance. Home is an expression of who you are and it is also a place that reflects what is meaningful and what matters to you. Home provides a retreat from a hectic or chaotic world. It is a place you often share with loved ones and is an environment that holds your treasured memories. All of these aspects of home can in fact provide for you when you are feeling stressed, vulnerable, injured, lost or unsure of yourself. It is a source of your resilience and strength.

But what happens when you are restricted to this environment and unable to leave freely? Even in the most pleasant and supportive environment, not being able to leave freely may override the positive gifts, and cause one to lose sight of its nurturing aspects. What happens to your view of yourself, your choices, and your own vitality when you are also feeling trapped at home? If this home is also a place where you are providing care for a loved one who is ill, suffering, hostile or unpredictable; if it is a place where there is conflict or disorder; if it is a place that you need a refuge or an escape from, then what is the impact on you as a Caregiver that is bound to this home?

Despite how positive or difficult the atmosphere is in your home, anytime you are feeling confined it is understandable that there might be stress directly related to the simple fact of feeling trapped.

When you are home the majority of the time because of your own illness or the needs of someone else, whether it is caring for an ill loved one, or home raising children, you may feel trapped, restless, bored, or frustrated. Now, you may also feel comforted or find you feel safe tucked up in your little nest. If however, you see home as a place where you are stuck or trapped, this will certainly influence or color your perspective or viewpoint regarding the experience of being home.

Anytime you are in the position where you feel you have no choice, or are confined or limited by something or someone else, it can be a difficult, wearing, and distressing feeling. Seeing yourself as stuck, or trapped, is going to have a negative impact on your wellbeing. What is happening inside when you feel trapped?



When you feel confined you may fight it or maybe give up and lose some of your vitality as a consequence. If seeing yourself as being bound to your home is one of the elements that; stresses, strains and drains your wellbeing, how do you change that? What can you do to alter your viewpoint?

Recognizing the real choices that you have and that you are making in your life is empowering and one potential way to positively impact your perspective. You are going to be far more distressed if you see yourself as powerless and trapped rather than making a choice even if that choice is how you decide to learn from the experience or how you are going to behave given the situation.

Think of how often you hear yourself or others state they have no control and no choice. "I have to do this. There isn't anyone else. There is nothing I can do. I am stuck with this. I don't have any options." If you do not see or accept the real choice that you make, you will naturally succumb to the bitter, angry, helpless, or hopeless feelings that can take over when you view yourself as trapped and without choice.

Seeing that you always have choices can be a tough idea to truly grasp. The choices you are making may be difficult. You may be choosing between one difficult solution verses another. For example, maybe you care for a loved one at home in part because the financial strain of a care facility is a consequence that would also negatively impact you in some way. There is still a choice there that you are making, a difficult and maybe even a seemingly impossible one yes, but a choice none the less, between one sacrifice over another.

We don't often choose the events of our lives. We don't choose the illness, the losses, the natural disasters, or the hardships, but you do in fact choose how you will make use of these events. If you cannot find a way to make meaning or take ownership and responsibility for the choices you make every day about how you conduct your life, then you run the further risk of being trapped in the grip of bitterness, helplessness, and blame.

Even in the most difficult of circumstances, you do continue to hold the responsibility and the power to choose whether that choice is to alter the situation or to alter your perspective.

It may seem like a silly mind trick to accept the choices that are yours to make, but in fact it can have powerful benefits for your wellbeing. For example, if each day I am saying to myself, "I chose to be the Caregiver for my loved one, not because I have to



do it, not because no one else will do it, I am doing it because I feel it is right for me, or I do it because I am committed to them in good times and bad, or maybe I do it because I don't want the consequences of not doing it."

Whatever it is that contributes to your choice of providing care, your ability to own the fact that, "I do it because I choose it," could free you of some of the burden that comes when you see yourself trapped and without choices.

Now, even when you are able to wholeheartedly commit yourself to the choices you make, there are still many sacrifices and struggles that you may encounter in your caregiving journey. Aside from coming to terms with the struggles of feeling trapped and recognizing choices, you must also contend with any number of potential obstacles and stressors that can impact your physical, emotional, mental and spiritual wellbeing.

How does caring for your loved one at home uniquely impact you? How can you develop strategies to offset the impact of Caregiving? Being confined can in and of itself impact your perspective. How may it impact emotions? Does being confined intensify some feelings? What might it do to your thinking? It brings to mind hearing parents at home caring for kids saying, "Oh it's so nice to talk to a grown up for a change!" How is your thinking challenged when you are more confined to home? How might being confined or limited in your ability to leave home impact your physical wellbeing? Finally, how does it impact your sense of you, your spirit or sense of meaning? Let's take a look at each of these aspects and explore what the consequences may be, and also identify some creative ways to support each of these aspects, even within the confines of home.

Let's first begin by looking at the impact on your emotional health.

In considering the impact being homebound or confined may have on one's emotional wellbeing, a couple of unique variables come to mind. One of the variables that I would consider relates to feeling restricted. When I picture powerful emotions that are bound to a contained environment, I imagine a pressure cooker.

Unless one is able to find a regular release, the emotions naturally build and intensify and the pressure and negative impact will more profoundly affect your whole system: physically, mentally and spiritually.

If, for example, you are getting more and more frustrated each day but not expressing or releasing it in some way, what do you imagine the impact may be? Maybe you will



resent your loved one or say harsh words you don't mean. Maybe you will get headaches, have trouble sleeping, or maybe you start turning inward and isolate yourself.

The very fact that you are confined can potentially heighten the intensity of your feelings, particularly of your energy depleting emotions like anger, impatience, frustration, boredom and despair. These difficult feelings in the context of being home, may take on larger dimensions if left to build and fester.

It is really a critical aspect to take note and bring attention regularly to how you are feeling. When identifying useful ways to take care for your feelings, we are not encouraging you to be consumed by how you feel or to put a big spotlight on them, holding on to the negative feeling for dear life. Caring for your feelings includes identifying or naming them so you can listen to the important information they are trying to tell you and releasing them so they aren't shoved into that pressure cooker waiting to blow, and in the interim ruining your health and wellbeing. We are talking about paying attention so that you are acknowledging, naming, learning from, and letting go of them so they are not building up and causing you harm.

All of your feelings are valuable sources of information if you don't listen to those feelings, you not only feel the negative effects on your wellbeing, but you will also be compromising your sense of self and what matters to you. If you are able to recognize and appropriately release your feelings, the more energy, confidence, and vitality you will bring to the present moment.

Caregivers who are more confined to home may find that this is even more difficult to focus in on their own feelings because they are potentially influenced by the feelings of those they care for due to the close proximity. When you are in such close quarters with a loved one who may be suffering or struggling with illness; who may be discouraged, angry, or confused, it is only natural that this is going to influence your own state of mind and emotions. Taking some time and attention for yourself by taking a time out can provide a boundary for you to settle back into your own skin and provide a break from taking on the feelings of another.

Slowing down enough to take a break and a breath and bring your attention back to yourself is one way that may help you pay closer attention to how you are feeling. Sometimes people have a time each day that they take to simply slow down and reflect. You don't have to meditate for hours to pay closer attention. You can simply take some time each day to sit and reflect.



There are many ways that you may practice paying attention to and releasing your feelings. Some people write in a journal. Some people meditate. Some pay attention and find release during exercise. The important piece is to attend to the vital information that your feelings are trying to relay to you. The important piece is to not push them aside so their force intensifies. What daily rituals do you keep to pay attention to how you are feeling? What ways have you found help you let go of feelings that are pent up? Is it exercise or meditation that helps you? Is it watching a sad movie and having a good cry? Is it digging in the garden or writing in a journal? Is it speaking up and setting some limits with someone? Maybe you find calling a friend who will listen to be helpful. Think about how you are feeling today and what may help you listen and care for the feeling you are having.

Next, let's look at the impact of caring for your loved one at home has on your thinking. Your thoughts may have become repetitive, worried, or what is called ruminative, thoughts. Maybe your thoughts have become negative, or maybe you are not having any thoughts that are inspiring or interesting. Maybe your mind is bored or unstimulated.

When you consider the worried or ruminative thoughts, consider it as your mind's way of trying to cope with something you fear, something that is unknown, or if it may be an attempt to control something you have no control over. Worry is oftentimes a way to avoid or not face something you fear may happen in the future. Worry is a terrible burden and a waste of your thinking. It is a trick you are playing on yourself to pretend you have control over everything that occurs by thinking that if you worry about it, it will prevent what you fear from happening.

So how do you get out of the loop of this merry go round of wasted thoughts? In order to interrupt this pattern, you may bring yourself to the present moment. If what you are worried or ruminating about isn't happening now then ask yourself how is worrying helping? Engaging in worry can be a habit that you need to notice and tell yourself to stop engaging your thoughts in. All the worry in the world is not going to keep something from happening. What it will do is give you a headache, a burning stomach, or a lousy night's sleep.

If your thoughts have been bogged down, focused on your many responsibilities and stresses and therefore have become dull, you may need to find ways within your environment to get re-inspired. You can learn something new. You can read about the world outside your windows. You can challenge yourself with interests or projects that



you have put on the back burner or never have had the time to pursue. Your mind can become dulled by confinement, or monotony, and can also easily come alive with an encouraging challenge. When your mind is engaged in something you find interesting, whether it is learning about history, growing a garden, taking a stab at writing a poem or knitting a sweater, you are not only waking up your interest and waking up your mind, but you are also giving yourself a boost and supporting your self-esteem. How do you engage your mind? What do you think you might like to learn more about?

Your physical wellbeing can be affected when you are both caring for the physical needs of your loved one and also when you are not able to come and go freely. There may be exhausting, sleepless nights and strained backs from lifting. There may be physical restlessness from not being able to come and go. Again, listening to your body is the first step. What is it saying? Most importantly, how can you begin to pay attention even within the confines of your caregiving duties?

Surprisingly, a little attention can go a long way. Small steps like making that doctor's appointment for yourself can reinforce that you matter and may help you get on track with caring for yourself. Setting some limits on what you can do physically, and asking for help is another way to practice self-care. A little bit of stretching in the morning or a 15 minute walk once or twice a day can boost your sense of wellbeing. Even doing a bit of housework is good exercise and has the benefit of making your environment more orderly and peaceful. Taking an afternoon nap or soaking your tired muscles in a candlelit bath is a way to care for your body that may have a payoff. Instead of eating on the run or rushing through fast food, you might try creating a healthy meal or make your meal a calm and restoring ritual by setting the table with flowers and slowly enjoying what you have made.

Attention to your physical wellbeing can reinforce that you matter and can help you relieve the stress and strain you feel with some simple daily moments of care. Consider how you might want to care for your physical wellbeing. Brainstorm some options, whether it is listening to a meditation tape, walking, and yoga, sitting and enjoying meals, stretching, or even taking your medicine as prescribed.

Finally, I want to take a look at the impact of being confined and focusing your energy and attention on caregiving, and the potential impact this has on your connections to others. Certainly caring for someone for whom leaving the home is difficult, maybe even next to impossible, brings a significant risk of being isolated from others. Maybe friends and family have distanced themselves or left you behind. You may struggle to



leave the home because it's too difficult for your loved one or find there are few options or supports to offer you a break. This is where creative thinking, persistence, and planning become critical to maintaining connections.

So, there is healing in connection. Caregiving for a loved one at home can compromise your connections to others and therefore your connection to your own unique meaning and value if your connections are left to dwindle. It may take a much more creative and purposeful effort to make and keep your connections going. It is possible though, despite the challenges, to develop and maintain your connections to family, friends and to your community if you are able to put forth the effort. This effort, every small step to reach out, will have a positive influence on you and has the potential of bringing back significant rewards. Have you noticed how a brief telephone call or a letter from a friend can brighten your whole outlook?

There are many ways you may reach out to connect to others. Maybe you use letters, telephones, computers, email, or Skype to connect with family and friends. Maybe you join an on line, over the phone, or in person support group. Maybe you connect with a neighbor over the fence and share gardening tips. Maybe you invite friends over to visit or share a meal. You may join an online class or Caregiver blog to connect with others. Whatever way you are able to connect with others, the better your spirits will be. It may not be easy, and it may mean getting creative and intentional to make these connections possible.

Making connections that can give you a boost, brighten your spirits, and reinforce your sense of purpose can also come in other forms. It may come in spending time with your favorite animal, taking your dog for a walk, petting your cat or riding your horse. Your pets can keep you connected and feeling valued and loved.

You may connect to the healing power of nature to brighten your mood. When you take notice of the beauty of a sunset, the flowering of trees in spring, the joy in chirping birds or the feel of a cool breeze, your attention to these gifts will pay back. The simple act of planting some seeds and watching them sprout can return a sense of wonder and gratitude for the natural world.

You can also connect to who you are by remembering what you value and contribute to the world. You may do this by thinking about the work you have done well, the children you have raised, or the care and loving attention you give others every day. So please, do not diminish your value but instead notice their humble significance and power. Every caring word, every prayer or good wish shared, every task completed, every bit of



knowledge shared, every well intended sacrifice, every contribution of attention, affection and care to your world and to another's wellbeing, cannot be replicated and cannot be minimized in its positive significance and contribution to the whole.

We hope our presentation has helped you find ways to expand your view of the world inside and outside your doors, and the options you may consider when you are struggling to care for yourself.

We hope that we have helped you to recognize and validate the challenges, the difficult choices you make and encourage you owning these choices which will empower you.

We hope that paying attention to your feelings, learning from them, and releasing them, will provide relief and clarity. Setting boundaries and limits, making room for your feelings and needs will take a concerted effort. You are worth the effort! You are worth the effort of attending to your feelings, of finding ways to stimulate your mind, to care for your physical wellbeing, to reach out to others, to enjoy the wonder of nature, to share your gifts and to remind yourself of your value and worth.

If you become discouraged or stuck, we at the Caregiver Support Line are here to remind you that you matter. It simply requires reaching out.

I hope you found this presentation a worthy use of your time. Thank you for listening. If you are a caregiver of a Veteran and would like to discuss any of the ideas offered during this presentation, I invite you to contact your local Caregiver Support Coordinator. You may also contact a social worker at the Caregiver Support Line at 1-855-260-3274. Thank you for all you do.